# Living with Cancer

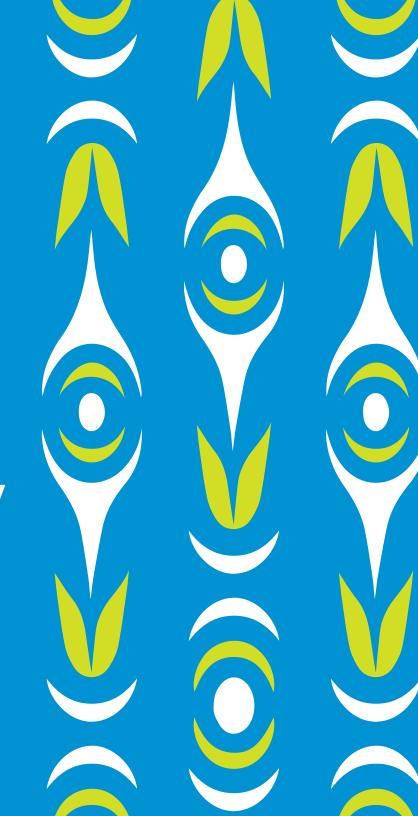
A resource to support First Nations people in BC on their cancer journey



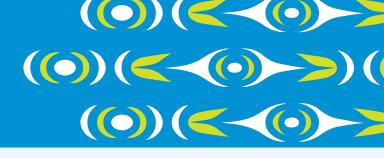
First Nations Health Authority Health through wellness



**Provincial Health Services Authority** 



### Acknowledgements



We raise our hands and gratefully acknowledge that this resource was created on the land and traditional territories of the First Nations peoples in BC. This booklet is based on an earlier publication *Living with Cancer—Everyone Deserves Support.* 

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Dr. Evan Adams, Health Leader Francine Gascoyne, Nurse & Health Leader Gail Gus Dr. Kelsey Louie, Health Leader Rev. Lily Bell Marilyn Belleau Monica McAlduff, Nurse & Health Leader Dr. Nadine Caron, Health Leader Dr. Nel Wieman, Health Leader Pamela Crema, Nurse & Health Leader William Samson

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### Introduction

If you or someone you love has received a cancer diagnosis, there are many supports available to you and things you can do to seek the best care possible. You are not alone on this journey.

This booklet offers information about the people and organizations available to support you, and it weaves in insights through the voices of First Nations people who have lived through—or are living through—a cancer journey. This booklet also includes space for you to write down your questions, notes and reflections. At the end of the booklet, there is a section to write the contact information of health care providers and supports and resources. A calendar and glossary of cancer related words is also located at the end of this booklet.

For more information, please use the QR code below for a list of resources and contacts that may be helpful for you, or visit <u>FNHA.ca/Cancer</u>

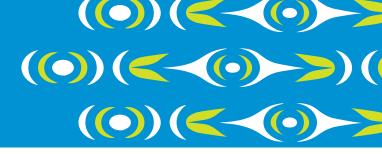


Our people, like our culture, are resilient. Many have taken life's obstacles and challenges placed in front of them head-on, enduring and overcoming the difficult times. For those embarking on their cancer journey, I encourage you to focus your energy on what you can control. The strength of spirit and fight from within for each of those entering their own unique battle is powerful. While a personal journey, I know our families, communities and culture continue to step up in a time of need to ensure they never face it alone.

- DR. KELSEY LOUIE, HEALTH LEADER, TLA'AMIN FIRST NATION

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## **Your rights**



### It is important to remember that your wellness journey is your own, and that you have the right to:

- > Seek support
- > Have a support person advocate for you, if you so choose
- > Receive culturally safe cancer care that is free of racism and discrimination
- Receive health care that meets your spiritual, cultural, traditional and mental wellness needs
- > Have mutually respectful interactions with all health care practitioners
- > Be treated as a whole person and not only as a patient
- > Have a medical professional clearly explain your health situation and treatment options

- > Ask questions or express any concerns you have about your health or treatment
- > Ask for clarification as often as you need
- > Request a second opinion from another health care professional
- > Be respected as the decision-maker about your health and treatment decisions
- Give or refuse consent for any procedure, for any reason
- > Ask health providers to keep your information confidential and to not share it without your consent
- > Ask for a copy of your personal health information records

The one thing I know from when I was going through this with my niece. It is your cancer. It is your decision and your body. What you need to do on your journey is your decision. This is you.

- GAIL GUS, TSESHAHT FIRST NATION

# Gathering support



## Your primary care provider



A primary care provider is a doctor or a nurse practitioner who can provide care to you when you have a cancer diagnosis. They are there to support you during and after your treatment.

If you do not have a primary care provider, call **8-1-1** to see if there is a health care provider near you. You can also call the First Nations Virtual Doctor of the Day program at **1-855-344-3800** 



### **BC Cancer**



BC Cancer oversees cancer care across BC, from prevention and screening to diagnosis and treatment.

BC Cancer also offers support programs, including patient and family counselling services, interpreters and pain management.

Indigenous cancer patient navigators are available at BC Cancer regional centres.

BC Cancer also has satellite clinics located around the province that are co-managed with the regional health authorities, where patients can receive treatment close to home.

# BC Cancer staff and your care team can support you in:

- Getting information about your cancer diagnosis and treatment options
- Listening and understanding your wholistic wellness and priorities
- Sharing supports and resources that may be useful for you on your cancer journey
- > Connecting you with an Indigenous cancer patient navigator, where available
- Identifying travel support options, virtual care and care as close to home as possible

## **Receiving a cancer diagnosis**



### If you or someone you love receives a cancer diagnosis, you may experience a range of thoughts and feelings.

You will likely have many questions about what is ahead. Depending on your diagnosis, you may need to make decisions quickly. Many people find it helpful to reach out to those they love and trust for emotional support.



I said, 'I do feel afraid.' He said, 'That's okay Auntie. Feel however you feel. Don't be ashamed because you feel scared. Just accept whatever feelings come at the moment.'

- REVEREND LILY BELL, HAIDA NATION



### Learning about your diagnosis

- > Write down your questions before you visit your health care provider so that you can bring them forward during your meeting
- > Write down the answers to your questions during the meeting so that you have a record of what was discussed (be sure to ask for permission from your health provider first)
- > Consider bringing a family member, friend or support person to your appointments to help you ask questions and/or take notes. They can also help you remember what was said by the health care provider
- Learn more by going to reliable online sources, such as websites for BC Cancer, the FNHA or the Canadian Cancer Society



I found it was important for me to use the medicine wheel concept to work on the physical, mental, emotional and spiritual areas of my life.

- MARILYN BELLEAU, ESK'ETEMC FROM ALKALI LAKE



#### I understand exactly what they're going through because I was there.

I'm a survivor of breast cancer 22 years now. In spite of the diagnosis of breast cancer in 2001, I was able to graduate from the University of Lethbridge with a Management Degree in 2003. I have continued to improve my health. Today I walk 10,000 steps a day. I recently completed the 10 km Sun Run in Vancouver in 2022 and 2023.

I read a lot of self-help books and do puzzles to keep my mind active. I enjoy sewing and have created a lot of projects: star blankets, drum bags and feather holders. I pray in the sweat lodge to help me emotionally and spiritually. I've also been helping other breast cancer survivors in my community just by being with them and being supportive. I'm finding that communication is really important to get them to connect with people, and I let them know that I understand exactly what they're going through because I was there. I had to lose part of myself in order to live.

- MARILYN BELLEAU, ESK'ETEMC FROM ALKALI LAKE

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# **Checking in with yourself**



### Questions you may want to ask your health care provider about your diagnosis:

What type and stage	of cancer do I have?
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Is my cancer slow growing or fast growing?

Is my cancer in only one place or is it in several parts of my body? What does this mean? What are the chances of surviving this cancer? How many people survive the same type of cancer that I have?

What are the treatment options?

Is there anything I can do to improve my health outcomes?

### Questions to ask your health care provider



### Take the time to reflect on how you are feeling by asking yourself:

Am I experiencing new feelings?

How can I manage these feelings in a good way?

Who do I feel comfortable sharing my feelings with (parent, grandparent, sister, brother, auntie, uncle, son, daughter, close friend, teacher, Elder, counsellor, etc.)? When is the best time for me to tell others about my diagnosis? What do I feel comfortable sharing with them? (Having information from your provider may help you decide how and what you wish to share.)

Do I need someone to come with me to my appointments to support and advocate for me?

Who makes me feel supported?

What is my medicine?

## **Practical support**

There are a number of practical supports to consider, depending on your diagnosis. You may need help with your daily tasks and responsibilities, and you may need to take time off work or be away from your family. You may also need to travel for tests and treatment. Talk to your health care provider about coverages and programs that may be available to help you with tasks, take time off work or travel for care. Documentation of appointment or a health care provider's referral may be needed.

Being a caregiver can involve offering physical and emotional support to a cancer patient. A caregiver may be paid or unpaid. A caregiver may be a spouse, family member or close friend. Acting as a caregiver can enhance the physical and emotional well-being of the person going through cancer, but can also affect the caregiver's own wellness. Being a caregiver takes time and energy. It is important that caregivers also take the time to focus on their own personal wellness when they are supporting someone with cancer.

- PAMELA CREMA, NURSE & HEALTH LEADER, SAULTEAU FIRST NATION - TREATY 8



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### Talking to your family about cancer



# When and how you plan to share your diagnosis with others is entirely up to you.

Your decision on when to share may depend on if and when you need support, such as support with daily responsibilities or with travel to and from treatment. It may be helpful to write down a plan and/or talk to someone you trust, such as an Elder, about what this looks like.

When speaking to family members about your cancer, you may want to speak to everyone together or to talk with each person individually. When talking with children, it can be helpful to share in a way that they can understand (such as through pictures or words that they know) and to provide space for them to ask questions and to be open to hearing their perspectives and feelings.

Not everyone will have the same approach to talking about cancer and sharing their diagnosis with others. It is entirely your decision about how you plan to do this. BC Cancer provides several resources with additional guidance and tips for how to talk to family and children about a cancer diagnosis.

You can access the resources through the BC Cancer website or the QR code at the end of this booklet.

- > Family support
- Talking to your children about a cancer diagnosis
- Talking to your teen about a cancer diagnosis

When you or someone you love receives a cancer diagnosis, it can be a shock. You may have questions. Be gentle with yourself. Depending on your diagnosis, you may need to make decisions quickly. It helps to gather support. Reach out to people you love and trust, and who are good medicine for you. Telling a loved one about your diagnosis may be the first step in your journey. There are many ways to share this information. Some people find it helpful to share with people they trust. Give yourself permission to ask for help from those around you.

Ever since I started this fight, I have had great support from my family and my partner of twenty plus years. I will not give up this fight with cancer.

- WILLIAM SAMSON, TSIMSHIAN, LAX KW'ALAAMS

# Talking to your health care provider about support



- > Are there support people at the cancer centre, such as patient navigators, social workers or spiritual or cultural wellness leads who I can talk to?
- > Where can I find support to help me process the thoughts and feelings I am having after being diagnosed with cancer?
- > If I have to fly or travel far for medical appointments, where can I get information on support for transportation and accommodation?

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- > Is First Nations Health Benefits and Services coverage or other program coverage available for my needs?
- > Who can help me prepare for what I might need as a result of my diagnosis?
- > Are there brochures or pamphlets that can help me learn about my diagnosis and treatment and the services that are available?

Supporting someone you love can be so rewarding; however, it can also be mentally and physically exhausting. It's really important for you as a caregiver to also take care of your needs so you can be in the best position to care for your loved one. Your own wellness is just as important.

- MONICA MCALDUFF, NURSE & HEALTH LEADER, SECWEPEMC



## What is an advocate?

### An advocate is someone you choose to speak up for you.

An advocate may be a family member, Elder, trusted friend or provider. They do not have to be a health expert. They should be willing to help you get the information you need, ask questions and support your decisions. You can have more than one advocate, and you can also be your own advocate.

#### An advocate does not make decisions for you, but they can help communicate your needs to health care professionals

and others. They can be a valuable partner at many different stages of your journey and do not need to be present at every step unless you would like them to be. Decide on your advocate's role based on what is right for you and talk with them about their role up front and throughout your cancer journey.

You have a right to know about your health, to be heard, to make your own health decisions and to be taken care of in a way that you think is best. When thinking about an advocate, you may want to ask yourself:

Do I need an advocate?

How would an advocate be most helpful for my needs?

Who makes me feel better and gives me strength?

Who in my life can help navigate the medical system with me and advocate on my behalf?

# **Tips for caregivers**



### If you are a caregiver who is supporting someone diagnosed with cancer:

- > Remember that being a caregiver requires permission and an invitation. Permission and/or invitation is needed for each part of a person's journey
- > Take time to learn what the person with cancer wants and needs and ask them to clarify how you can best support them
- If you are attending appointments with the cancer patient, it can help to write down information shared by health care providers so that you have a record on hand for future reference.

- > Some areas a person may need help with could include:
  - > understanding their treatment options
  - > knowing where they can access medical, traditional or other supports; and
  - taking care of their practical needs, such as daily care, home maintenance, groceries or child care
  - supporting personal care needs, like bathing and dressing
  - helping with personal planning decisions and paperwork (e.g., choosing a substitute decision maker and power of attorney)

Taking care of yourself and nourishing your spirit is key when providing care to a loved one in their healing journey.

- FRANCINE GASCOYNE, NURSE & HEALTH LEADER, NUXALK AND XAXLI'P FIRST NATIONS



### **Questions to ask yourself as a caregiver**



### As a caregiver, you may want to ask yourself:

Where can I learn more about being a caregiver?

What do I need for my own personal wellness?

Will I know when I need to ask for help to support my own wellness?

Is there a support group for caregivers in my area?

Does my local cancer centre offer support for caregivers?

Do I have anyone I can talk to about my feelings?

Who will I reach out to for help when I need physical, mental, spiritual or emotional support?

## **Understanding cancer**



Cancer is a disease that starts in our cells and can occur in almost any organ or tissue of the body. Our bodies are made up of trillions of cells. Normally, our cells grow and divide to form healthy new cells and any damaged cells are destroyed or repaired. However, sometimes these damaged cells are able to create copies of themselves and clump together into tumours.

Tumours—or lumps—are classified as either benign (not cancer) or malignant (cancer). A benign tumour is one that does not spread or invade nearby tissues. Cancerous (malignant) tumours can grow quickly. They may affect nearby tissues and can spread to other parts of the body, interfering with the function of an organ or body system.



# When it comes to your health, knowledge is power.

A cancer diagnosis can be a scary thing, but learning more about your diagnosis and treatment options can take some of that fear away and support you and your family in making informed decisions.

Talk to your health care provider, ask questions, learn about the resources available to you through the FNHA and BC Cancer and reach out to friends, family, Elders or community leaders who have been through a similar journey.

Whether it's you or a loved one who receives the diagnosis, these supports can help you navigate your path forward.

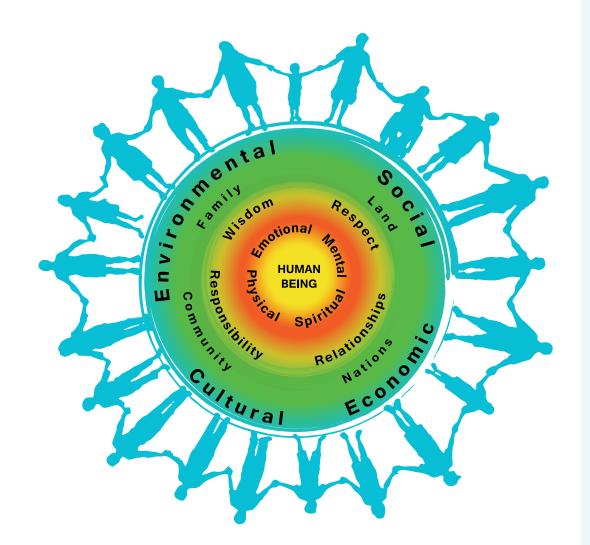
- DR. NEL WIEMAN, HEALTH LEADER, LITTLE GRAND RAPIDS FIRST NATION, ANISHINAABE



# Many ways of healing

### The First Nations Perspective on Health and Wellness





The First Nations Perspective on Health and Wellness aims to visually depict and describe the First Nations Health Authority Vision: Healthy, Self-Determining and Vibrant BC First Nations Children, Families and Communities.

For more information, please visit:



# Wholistic wellness during serious illness

Every person deserves to experience wellness throughout their lives, whether they are experiencing good health, sickness or serious illness.

It is especially important to continue thinking about and supporting your wholistic wellness while managing a serious illness like cancer. Wholistic wellness involves being balanced and well in your physical, emotional, mental and spiritual well-being.



## **Wholistic wellness**



### **Physical wellness**

Taking care of your physical wellness is an important part of managing your serious illness. Eating foods from the land and being as active as you are able to may help keep your strength up. You can call 8-1-1 to talk to a nurse or dietitian for support.

### **Spiritual wellness**

Living with cancer can be a time for personal reflection or to explore religious or cultural practices. It can be a time to renew your focus or to spend more time with people that energize you. Everyone's path and beliefs are different and should be respected.

### **Emotional wellness**

Emotions when living with a serious illness may frequently change. Spending time with and talking to people you trust can help you feel well. Remember to take time to do things that bring you comfort and to surround yourself with people who lift you up.

### **Mental wellness**

Staying mentally well is helpful as your approach different phases in your journey. Knowing what to expect and feeling prepared can help. Speak with your health care team for information and support. Mental wellness can be nurtured by connecting with others and the land. Counselling and medicine can also be helpful. If you need to speak with a mental wellness professional or counsellor, speak with your health care team to find resources to support you.

# Traditional and cultural wellness

Cancer affects the body, mind, heart and spirit. A cancer diagnosis can affect all aspects of our lives from our relationships and work life to our mental, spiritual, emotional and physical well-being. It is important to think about all of these elements as you move forward with your journey.

Medical terminology can be new to cancer patients. Similarly, the beliefs and practices of Indigenous traditional wellness and healing can be unfamiliar to health care providers.

Every person with cancer has a right to understand their diagnosis, to understand their treatment options and to have their questions heard and answered. It is important to discuss your wholistic wellness and healing priorities and decisions with your medical team.



# Traditional, cultural and spiritual supports



Traditional, cultural and spiritual supports can include activities like being on the land, drumming, singing, smudging, brushing and ceremony. It can also include care from an Elder, traditional healer, sacred knowledge keeper or other spiritual leader. Examples of traditional medicines include teas, salves, tinctures, bear grease and eagle fans.

Each person and community can have their own teachings and practices when it comes to healing and wellness. Some of these traditions might be widely practiced and others can be unique to specific communities.

You may have an interest in accessing both traditional and western medical practices as part of your cancer care. If you need help connecting with a traditional, cultural or spiritual wellness support person, reach out to an informed community member or your local Indigenous health organization.

Communicate your wishes to your health care provider so that you can be supported with the information and coordinate the care you need.

Talk to your health care provider to find out if there are any potential interactions between western and traditional medicines. This information can help you make your own health care decisions. You can ask to have your wholistic priorities and treatment decisions documented in your care plan.

You have the right to choose what treatments and supports services are the best fit for your health and wellness journey.

# **Spiritual care services**

### Health authorities offer spiritual care services and many buildings have sacred spaces available for your use.

There are also policies in place to support cultural practices like smudging in hospitals and other settings. Health authorities have Indigenous Health Teams with patient navigators or liaisons who can help you.

Spiritual health professionals are members of your care team. They are trained to provide comprehensive spiritual health care and emotional support to patients, families and health care staff. You may wish to request the support of a spiritual leader specific to your particular beliefs or religion.



My role as a First Nations surgeon is to share where my expertise is, but I am not an expert in traditional medicine. I am so fortunate to learn from my patients about traditional healing practices. My job is to do the best I can, and absolutely respect each patient's perspective. I can respect an individual's beliefs, even if it is different from what I've been trained in.

#### - DR. NADINE CARON, HEALTH LEADER, SAGAMOK ANISHNAWBEK FIRST NATION

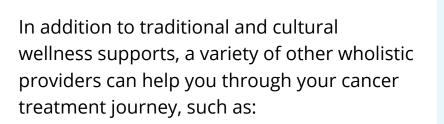
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Living wisely with good health is something we have always done, and we are often reaching back into our ancestral knowledge—our traditional ways of being and knowing—to reaffirm how we can live healthier lives today and tomorrow.

- DR. EVAN ADAMS, HEALTH LEADER, TLA'AMIN NATION



## **Other complementary medicine**



- > Yoga and meditation practitioners
- > Nutritionists
- > Massage therapists
- > Clinical counsellors
- > Acupuncturists
- > Physiotherapists
- > Naturopaths
- > Homeopathy
- > Chinese medicine

### Coordinating different ways of healing: Traditional and western medicines

Talk to your health care provider to share any traditional and cultural wellness priorities. You can also discuss any potential interactions between western and traditional medicines. This can help provide you with the information you need to make your own health care decisions. For myself, I was trying to find that balance between western and traditional. That's what was going on with me. It was something I was already practicing before. I put my faith in both and it all came down to my faith. I didn't rank one against the other. I didn't do that. It was really important for me to put my faith out there. And I had such a huge team without me even asking for it.

It's like when I was in the hospital, somebody sent a traditional healer there for me and he did some work on me. He did some chanting and after it was all done, the nurse who came in and did my vitals says she found that every time there was traditional work, the vitals were really good. She was open to it.

We need more medical staff to be open to our traditional values.

- GAIL GUS, TSESHAHT FIRST NATION



## **Questions to ask**



You may want to ask yourself about traditional, cultural and spiritual wellness:

Is traditional and/or cultural wellness and healing right for me?	Am I comfortable discussing my traditional and cultural wellness wishes with my health care provider?	
What type of healing work might be best for me?		
Who can I connect with to access traditional and cultural wellness supports?	If I am not comfortable discussing my wishes with my health care provider, do I	
Are there any key health care decisions I will need to make?	know someone who can help me?	

## Tips for talking to your health care provider

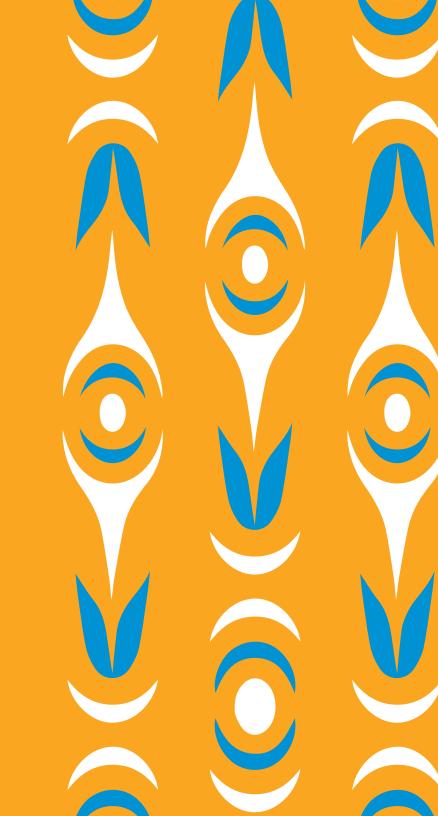


## When talking to your health care provider about traditional, cultural and spiritual wellness:

- > Ask for extra time at your next appointment to discuss traditional and cultural wellness and healing
- Gather as much information as possible about the traditional and cultural wellness and healing practices you are interested in
- > Consider bringing in a close friend or an Elder/ healer to support you in your discussion with your health care provider
- > Be prepared that the health care provider may not have knowledge about or be comfortable offering thoughts on traditional wellness and healing practices and medicines

- > Remember you have the right to have your priorities and decisions respected
- > Ask that your traditional and cultural healing priorities and decisions be documented in your health care plan
- Write down notes from your conversations with your health care provider and any information that will help you with your decision-making

## Choosing treatment paths



## **Choosing treatment paths**

Your health care team may recommend surgery, chemotherapy, radiation therapy or any combination of these to treat your cancer. The next few pages discuss the different types of treatments and questions you may wish to consider.

Remember, it is your right to ask as many questions about the recommended treatments so that you know what to expect and feel comfortable making a decision.

## Types of medical treatment and cancer drugs

The type of treatment that is required for each person's type of cancer is dependent on many factors. The three main types of cancer treatment are surgery, chemotherapy and radiation. Other forms of cancer treatment may also be recommended.



## **Choosing treatment paths**



#### Surgery

Surgery is used for many reasons, including diagnosing and treating cancer. Surgery can be used to remove a tumour (lump) or reduce the size of a tumour. Aftercare and recovery following surgery may vary, depending on the type of surgery and the other medical treatments you may be receiving.

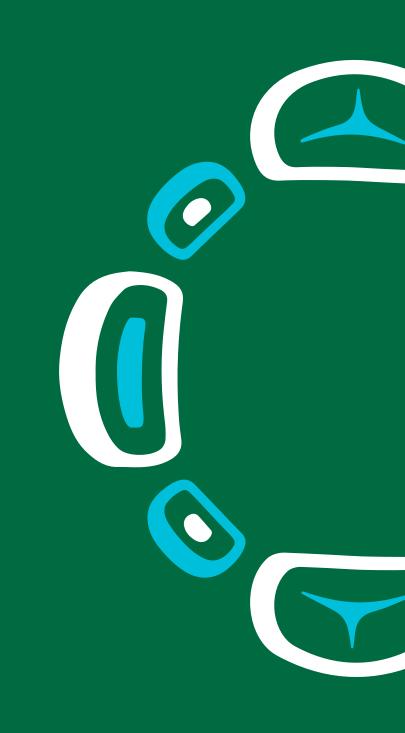
#### Chemotherapy

Chemotherapy uses special medicines or drugs within the body to treat cancer. These medicines may be given as pills, injections or intravenously (IV). The drugs are carried by the blood throughout your body to reach the cancer cells. The frequency and length of your chemotherapy treatment will be specific for your cancer. Chemotherapy can be given every day, every week or every month at regular intervals. You will likely have questions about the cancer drugs and combinations of cancer drugs being recommended to treat your cancer.

#### **Radiation therapy**

Your cancer may be treated using radiation, which uses high-energy rays to kill or shrink tumours (lumps). It does so by destroying cells or slowing down their ability to reproduce and grow. Radiation therapy can be used on its own or in combination with cancer drugs. Radiation can also be used to help shrink a tumour before surgery. Ask questions to learn more about the treatment options that may be recommended to you. This can help you understand what to expect and support your decision making.

## Travel and treatment



## **Travelling costs and coverage**

You may need to travel to access cancer treatment services. Ask your health care providers and regional BC Cancer centre what travel and accommodation coverages and supports might be available to you. Documentation of appointment or a health care provider's referral may be required for travel/accommodation coverage.

If you have an extended health benefits provider through your employer, consider looking at what your coverage plan might offer.

Let your provider know if you live in a rural or remote area, or if travel to health care may be a challenge for you. Ask your health care providers if there are ways to reduce travel for care. Telehealth or telephone based appointments might be possible. Coordinating different appointment during one trip might also be an option.

## Travel and accommodation contacts:

- > First Nations Health Benefits at 1-855-550-5454
- Travel Assistance Program (TAP), Health Connections and more
  1-800-663-7867
- > Extended health provider (e.g. Canada Life)

## Questions to ask about your treatment

Will I need surgery? Chemotherapy? Radiation?	What are the short-term and long-term side effects of this treatment?	How can I support my mental health and wellness during treatment?	How can I manage these side effects?
Where will I go for treatment? Is this the closest option?	How will I know if this treatment is working?	l am interested in traditional and cultural	What are my treatment options and what would you recommend for me? Why do you feel this is the best option
How often will I need to receive this treatment? For how long? Who will be providing my treatment?	Will I be able to continue my regular activities (such as work, housework, driving, exercise, etc.)?	supports to be a part of my treatment. How can we integrate this into my care plan? Are there any potential interactions to know about?	for me? What can I eat during treatment? Are there foods I should avoid?

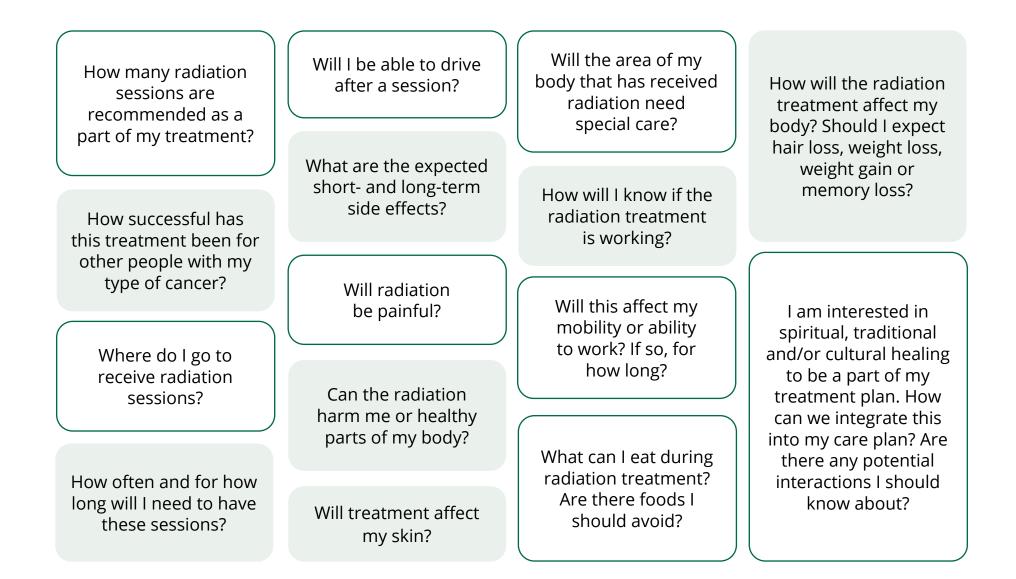
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## Questions to ask about chemotherapy treatment

How will the chemotherapy treatment be given to me? Orally? Through injection?	Will I be able to drive after receiving a chemotherapy treatment?	How successfully has this treatment been for other people with my type of cancer?	What can I eat during chemotherapy? Are there foods I should avoid?
Where do I go to receive treatment? At a BC Cancer centre, hospital or at home?	Is there any pain involved? If there is pain, how can I manage it?	How will I know if the chemotherapy is working?	I am interested in spiritual, traditional and/or cultural healing to be a part of my overall treatment plan.
How long and how often will I need to receive the treatment?	Will this affect my mobility or ability to work? If so, for how long?	How will this affect my body? Will there be hair loss, weight loss, weight gain or memory loss?	How can we integrate this into my care plan? Are there any potential interactions I should know about?

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## Questions to ask about radiation treatment



## Tips when asking questions

#### When working with your health care providers to understand your treatment options, you may wish to:

- Bring your support person or advocate with you to help you take notes, ask questions on your behalf and recall information
- > Write down the information shared with you and any instructions provided (you can use the "My Wellness Plan" at the back of this book for this)
- > Ask questions about the medications and procedures being prescribed
- Inform your health care provider if you are using or planning to use traditional and cultural medicines and supports
- > Discuss any supports you may need to help access treatment plan services (e.g. medicine schedule or travel/accommodation supports)

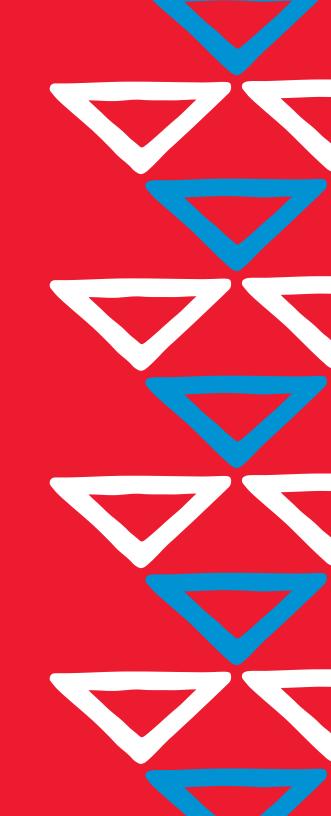


### **Cancer treatment and work**

## Things to consider about how your treatment might affect your work:

- > Adapt your work schedule: If possible, ask your employer if you can explore flexible working options, such as working from home some days or working part time. This can help give you the space and time to take care of yourself. Consider taking a leave from work if this is an option for you
- > Ask for support at home. Getting help at home can give you more energy for work. See if you can share daily chores with friends and family members who have offered to help

The journey after treatment



## The journey after treatment



When your active treatment of surgery, chemotherapy and/or radiation is over, you will likely require follow-up care from your regular doctor or specialist. This process may involve travel to and from treatment centres for testing and care.

This part of the journey can involve a range of thoughts and emotions. Taking care of your wholistic well-being continues to be important during this time. Many cancer centres have counsellors you can talk to about what you are feeling and experiencing.

Be gentle with yourself after your cancer treatment. Others may expect you to return to the routines you had before your diagnosis. However, this may not be possible right away. Keep a close eye on how you are feeling and what you need to make your transition back to life after treatment as smooth as possible.

#### **Returning to work**

Some people find it helpful to talk with a counsellor to develop a return-to-work plan that you can share and discuss with your employer, if this applies to you.

You might also find it useful to talk with a counsellor to explore your thoughts and feelings and to review healthy ways to cope and strategies for asking others for what you need.

## Questions to ask about the end of your treatment



Will information about my treatment and follow-up care plan be sent to my family doctor or nurse practitioner?

Can I receive a copy of my treatment information? For example, the list of surgeries, information about radiation treatment, or names of cancer drugs or hormone therapy, etc. Will I need to undergo regular checkups after treatment? How often, where and with whom?

When can I expect to return to my normal routines after treatment? What if I need help to transition back to normal routines? What resources are available for me?

Who do I speak to if I have questions regarding my care plan, health status or side effects?

How can I expect to feel physically, mentally and emotionally after treatment?

What can I do to support my wellness and recovery after treatment? I am interested in spiritual, traditional and/or cultural healing as part of my follow-up care. How can this be integrated into my care plan? Are there any potential interactions I should know about?

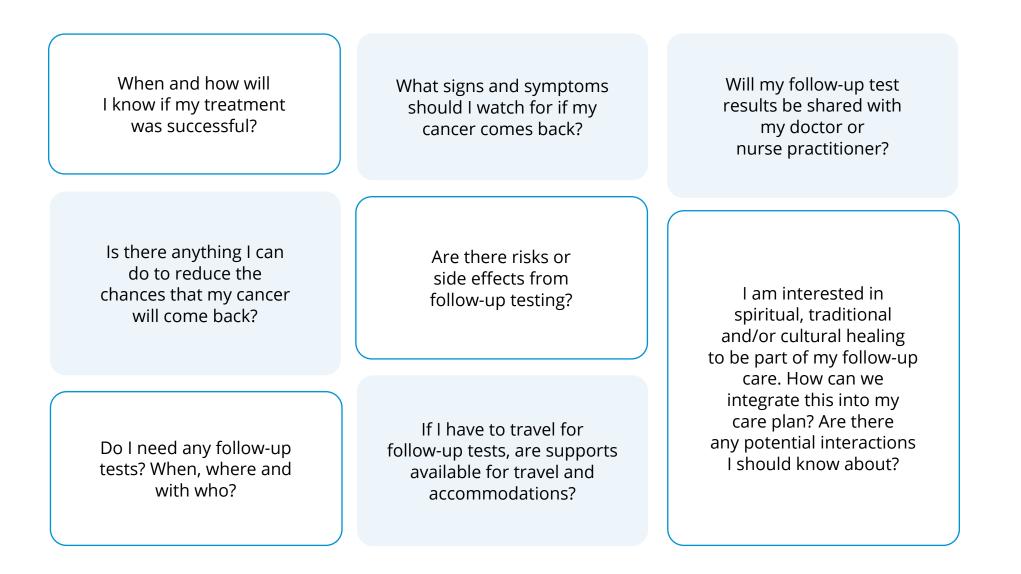
## **Returning to work after treatment**

## Things to consider when returning to work after treatment:

- > Talk to a counsellor for support, if needed. If you have First Nations Health Benefits coverage, call **1-855-550-5454** to ask about counselling and other mental health service coverage options
- > Talk with your health care provider about a manageable time frame for returning to work
- Set realistic expectations about what you can do when you return to work
- > Ease back into work slowly. If possible, try some practice days with light duties, reduced hours and frequent breaks to make sure you are both physically and emotionally ready to return to work



## Questions to ask about follow-up care



## Wellness tips after treatment

#### Things to keep in mind for your wellness after your treatment has ended:

- > Be gentle with yourself
- You may wish to share your experiences and emotions with your advocates and support people
- > Remember that even when you have completed treatment, your friends, family, providers and other support people can still be part of the journey
- Consider whether you want to include traditional wellness as part of your wellness path after your treatment



## **Advanced cancer and palliative care**



#### Sometimes cancer advances to a stage referred to as "advanced cancer" or "terminal cancer" and may require palliative care.

Palliative care focuses on providing a good quality of life and supporting you to be as comfortable and pain free as possible. Palliative care may involve medicines, treatments, physical care, social services, mental health care and spiritual support for you, your family and others who are helping to care for you.

Many palliative care services are available through regional health authorities, First Nations health centers and supports in your community. The type of care you receive can change over time as your illness and needs change.

Receiving a diagnosis of advanced or terminal cancer may leave you with a wide range of thoughts and emotions. Know that you are not alone.

You may want to discuss the physical symptoms of advanced cancer with your health care provider. You may also want to ask your care team if there are any supports available to you while you process this news.

There may be a number of decisions you need to make when receiving the news of advanced cancer. You may want to discuss your plans with your friends and family.

## See <u>FNHA.ca/Cancer</u> for more information about palliative care and end-of-life.

Health, legal and financial matters to consider

## **Know your options**

## Know that there are a range of options available to you, including the option to:

- > Choose a substitute decision-maker who can make certain decisions on your behalf related to your personal care, health care treatment or financial affairs
- > Write down instructions about your wishes for medical care if you become unable to communicate or make decisions yourself later on
- > Choose an enduring power of attorney who you give the legal authority to act on your behalf in relation to your finances and property if you can no longer do so
- > Write a will that gives legal instructions about how you want your estate to be handled when you pass and how you would like any family members, like children, to be cared for. For a will to be valid, it must be in writing. It can be typed, handwritten or in electronic form



### **Questions to ask about palliative care**



For people who have the same cancer diagnosis that I have, how long do they usually live?

Are there any treatments that will make me feel better or will help me live longer?

Are there any potential side effects from these treatments?

Are there any major decisions or things to do that I should consider at this point?

How can I be supported to continue to live at home as long as possible?

Are there supports for my family or friends as caregivers?

What does the end-of-life look like?

What is a hospice and when might I need to go to one?

If I have to go to a hospice, what are the steps that my family and I need to take?

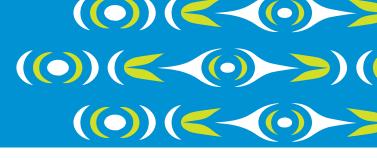
Can I choose which hospice I go to and the kind of services I receive?

What are the best ways to manage pain and stress or worry? Can my loved ones visit me at a hospice or can I go home sometimes?

I am interested in spiritual, traditional and/or cultural healing to be a part of my end-of-life care. How can we integrate this into my care plan? Are there any potential interactions to know about?

## Resources and wellness planning





#### 1-855-344-3800

First Nations Virtual Doctor of the Day Program

#### 1-844-935-1044

or <u>quality@fnha.ca</u> The FNHA's Quality Care & Safety Office

#### 1-855-550-5454

The FNHA's Health Benefits Program

#### 1-800-663-9203

Mammography appointment booking with BC Cancer

#### 1-800-739-7367

Options for Sexual Health to find a clinic offering Pap tests

#### **1-877-70-COLON** To find a lab to get a FIT kit

**1-877-717-5864** Lung Screening Program

**1-888-590-3123** Tsow-Tun Le Lum Cultural Supports

**1-800-721-0066** Indian Residential School Survivors Society Cultural Supports

#### **1-800-588-8717** KUU-US 24/7 Indigenous Support Line

IU-US 24/7 Indigenous Support Lin

**310-6789** (No area code)

24/7 Mental Health Support Line

#### **Online resources:**

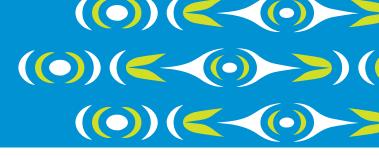


#### <u>FNHA.ca/Documents/FNHA-Living-</u> <u>With-Cancer-Resources.pdf</u>

#### 8-1-1

Registered nurse or dietitian with HealthLink BC





This list of words is meant as a helpful reference when reading or talking about cancer information.

### Active surveillance (also called watchful waiting)

Using tests and exams on a regular basis to watch for changes in a person's health.

#### Advocate

A person asked to publicly provide support and speak on your behalf if you request it.

#### Aggressive

When cancer is fast growing or treatment is more intense than usual.

#### Anesthetic

A drug that causes the loss of feeling or numbing of pain in some part or all of the body.

#### Benign

Not cancer.

#### Biopsy

Taking cells or tissues from the body to look at them under a microscope.

#### Bone scan

A test that injects a very small amount of radioactive dye into the blood to create images of bone.

#### **Bowel movement**

Poo or stool, often recorded on medical charts as "BM."

#### **Brain cancer**

Cancer that starts in or spreads to the brain.

#### **Brain scan**

A test that injects a small amount of a radioactive substance into the blood to create an image of the brain.

#### Brain tumour

A tumour in the brain that may be benign (not cancer) or malignant (cancer).

#### Cancer

The name for diseases in which abnormal cells grow out of control and can spread to other parts of the body.

#### Carcinogen

Anything that is capable of causing cancer.

#### Cell

The most basic, smallest unit of all living things.

#### Cervix

The lower, narrow end of the uterus that opens into the vagina.

## 

#### Chemotherapy

Treatment that uses drugs to kill or destroy cancer cells.

#### Colon

The longest part of the large intestine, sometimes called the large bowel (where stool comes from).

#### Colonoscopy

A test that uses a hollow tube with a light and camera to look inside or treat the colon.

#### Colostomy

An operation to make an opening from the colon to the outside of the body through the belly. A special bag (colostomy bag) is attached to the outside of the body to collect stool from the colon.

#### **Complementary treatment**

An approach to wellness and healing that incorporates non-western practices (such as acupuncture, mindfulness, Indigenous traditional medicine, etc.).

#### Cone biopsy

Removing a tiny cone-shaped piece of tissue from the cervix to look at the cells under a microscope.

#### Consent

Giving permission.

#### CT scan (computed tomography)

A test that uses a computer to put many X-rays together to create a 3D picture of organs, tissues, bones and blood vessels in the body.

#### **Cultural humility**

A process of self-reflection to understand personal and systemic biases, and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.

#### **Cultural safety**

An outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.

#### Diagnosis

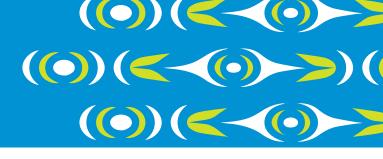
The process of finding out a person's health problem.

#### Endoscope

A hollow tube with a light and a camera that is used to look at or treat organs or structures inside the body.

#### **Family history**

The medical history of a person's family, including mother, father, brothers, sisters and grandparents. A family history may show a pattern of certain diseases in a family.



#### Fatigue

Feeling extremely tired or not having enough energy.

#### FIT (Fecal Immunochemical Test)

Testing a small stool sample for traces of blood.

### H. pylori bacteria (Helicobacter pylori)

A type of bacteria that causes inflammation and ulcers in the stomach and small intestine. H. pylori infection is associated with an increased risk of developing stomach cancer.

#### Histology

The study of cells or tissue types by viewing them through a microscope. This method can be used to classify tumour types and best treat each individual cancer.

#### Hormonal therapy

A common method of medical treatment for certain cancers and other conditions that involves the use of hormones to manage the illness.

#### Hormone

A chemical produced by the body that is released by a gland or cell in an area of the body that signals and affects cells in another region of the body. Responses to hormones depend on the signal sent and can involve, but are not limited to, mood, immune function, metabolism and reproduction.

#### Hospice

A place to care for people who are near the end-of-life. Hospices provide palliative care, which is a type of specialized care focused on providing patients with relief from symptoms, pain and stress. The goal is to improve quality of life for both the patient and their family.

#### Immune system

The warrior cells and organs that defend the body against infection, disease and other materials that enter the body.

#### Inoperable

A disease or tumour that cannot be treated with an operation.

#### IV (Intravenous)

Within or into a vein (e.g., an IV drip).

#### Leukemia

Cancer that starts in blood-forming tissue such as bone marrow. It causes large numbers of abnormal blood cells to form and enter the bloodstream.

#### Lumpectomy

An operation to remove a lump or tumour in the breast along with a very small amount of healthy tissue around it.

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#### Malignant

Cancer or cancerous.

### Mammogram (also called screening mammography)

An X-ray picture of the soft tissue of the breast.

#### Mastectomy

An operation to remove part or all of a breast (or breasts). Different types of mastectomy include total mastectomy, radical mastectomy and modified radical mastectomy.

#### **Medical history**

A record of someone's risk factors, symptoms and past medical events and problems.

#### Melanoma

A type of skin cancer.

#### Metastasis

The spread of cancer from where it started to other parts of the body.

#### MRI (Magnetic Resonance Imaging) scan

A test that uses a magnetic field to make very detailed pictures of the inside of the body.

#### Nerve damage

Damage to nerves or the nervous system resulting in a variety of symptoms.

#### Nurse practitioner

A registered nurse with extra training and education.

#### Oncologist

A cancer doctor.

#### Operable

Can be treated with an operation.

#### **Operation (also called surgery)**

Cutting into the body to look for disease, or to remove tumours, or to remove or repair an organ or a part of the body. Operations are done in a hospital with anesthetic.

#### **Palliative care**

Specialized care focused on providing patients with treatment and support for the symptoms, pain and stress of a serious illness that cannot be cured. The goal is to improve quality of life for both the patient and their family.

#### Pap smear or Pap test

A test that swabs cells from the cervix and looks at them under a microscope.

#### Platelet

A type of blood cell that helps blood to clot (to slow or stop bleeding). Also called thrombocyte.

#### Polyp

A small growth on the lining of an organ or body part.

#### Prognosis

The expected outcome or course of a disease.

# 

#### **Radiation therapy**

A treatment that uses high-energy rays to kill cancer cells or shrink tumours.

#### Recurrence

Cancer that has come back after remission (a period of time when there were no signs or symptoms of disease).

#### **Recurrent disease**

The return of a disease after remission.

#### Remission

A period of time when the signs and symptoms of cancer get better or go away.

#### Rights

Principles of freedom and entitlement.

#### **Risk factor**

Something that increases the chance of developing a disease.

#### Safe and informed

A phrase used to draw attention to the need to communicate to ensure that any medically prescribed treatments, medications or procedures will not have adverse reactions (side effects) when combined with other chosen treatments.

#### Screening

Checking for cancer when there are no symptoms. Early detection can better the chance of a cure. Examples of cancer screening tests include a mammogram, colonoscopy and Pap test.

#### Side effects

Unwanted symptoms caused by a treatment or procedure such as fatigue, nausea, vomiting, pain, brain fog, hair loss and mouth sores.

#### Stage

The steps of cancer (on a scale of one to four) are based on specific

criteria for each type of cancer, including the size of the tumour, whether there are cancer cells in the lymph nodes and how far the cancer has spread in the body.

#### Steroid

Examples of steroids include cholesterol, estradiol, testosterone and anti-inflammatory drugs.

#### Support

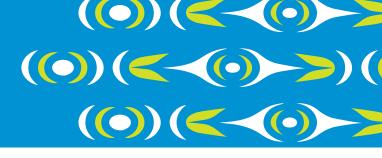
To give assistance in any way.

#### Surgery

Cutting into the body to look for disease, or to remove tumours, or to remove or repair an organ or a part of the body. Surgery is done in a hospital with anesthetic.

#### Symptom

A physical or mental sign that may indicate a person has a disease or condition.



#### Toxicity

The extent or degree to which a substance can damage an organism (or a portion of it).

#### **Traditional medicine**

Traditional medicine means different things to different people. It can include cultural practices such as singing, drumming, ceremony or ingesting substances.

#### **Traditional wellness**

Traditional wellness is a term coined by the First Nations Health Authority to encompass Indigenous traditional practices, approaches, medicines and knowledge, and to reflect a wholistic model of health.

#### Tumour

An abnormal mass of tissue formed when cells grow and divide more than they should. Tumours may be benign (not cancer) or malignant (cancer).

#### **Tumour marker**

A substance in the blood or body fluids that may suggest a person has a certain type of cancer.

#### Ultrasound

A test that uses high-frequency sound waves to make pictures of structures and organs inside the body.

#### Wellness

An approach to overall health that strives to balance mind, body, and the emotional and spiritual elements in a person's life.

#### X-ray

A type of high-energy radiation that produces a picture of the bones and other structures inside the body. In low doses, X-rays are used to diagnose cancer by making pictures of the inside of the body. In high doses, X-rays are used to treat cancer.

## FNHA.ca/Cancer



First Nations Health Authority Health through wellness



**Provincial Health Services Authority** 

